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ABSTRACT

This report provides descriptive information on variations in selected features of state and local early intervention systems. Information was gathered from 20 states as part of the National Early Intervention Longitudinal Study (NEILS). Results indicate a considerable variation along a number of dimensions, including: eligibility criteria; type and number of agencies involved in early intervention; the ways agencies have coordinated their efforts; and models of intake and service coordination. The report also raises questions about how these variations could be significant to children with disabilities and their families. (Contains 23 references.) (Author/SG)

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## NATIONAL EARLY INTERVENTION LONGITUDINAL STUDY (NEILS)

# STATE-TO-STATE VARIATIONS IN EARLY INTERVENTION SYSTEMS

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## BACKGROUND

Before the passage of P.L. 99-457 in 1986, a variety of public and private agencies were involved in providing early intervention services. Exactly how many agencies, which agencies, whom they served, and the roles they played varied from state to state (Gallagher, Harbin, Eckland, and Clifford, 1994). Congress recognized both the preexisting state diversity and the need to coordinate services across agencies when it crafted the legislation that created the Early Intervention Program for Infants and Toddlers with Disabilities (formerly known as Part H and now known as Part C of the Individuals with Disabilities Education Act, IDEA). States were required to identify a lead agency to administer the program, develop a definition for developmental delay, and decide whether they would serve children who were at risk and their families. To address the coordination of multiple agencies involved in service delivery, states were required to create an Interagency Coordinating Council (ICC) and provide service coordination to each family receiving early intervention services.

Although the federal legislation provided states with funds to build coordinated, interagency systems of early intervention services, very little is known about the characteristics or operation of these systems (Florian, 1995). By "system," we mean the participating agencies and processes through which children and families enter early intervention, are evaluated, receive service coordination and other early intervention services, and transition out of early intervention. Much of the literature on the delivery of early intervention services has addressed program models or delivery of interventions (e.g., Bryant and Graham, 1993), with little discussion of the characteristics of the service systems in which they are embedded. The Division of Early Childhood Recommended Practices (DEC Task Force on Recommended Practices, 1993), for example, addresses service delivery models, curricula, and interventions, but does not address interagency coordination, intake, or service coordination. The lack of descriptive information on how state and local systems are organized to provide early intervention is significant because one of the goals of the federal legislation was to help states to coordinate the resources and services for infants and toddlers that already were available in the states (Safer and Hamilton, 1993). Indeed, a review of recent statewide evaluations of Part C programs indicates that one critical issue is gaining a better understanding of how systems are organized and how systems' factors relate to service coordination, as well as child and family outcomes (Roberts, Innocenti, and Goetze, 1999).

Many questions persist about early intervention systems around the country. Which agencies provide early intervention services? Whom do they serve? What does interagency coordination look like at the local level? How much variation is there across states in the systems they have built? What models have localities adopted for intake and service coordination?

The organization of early intervention systems in states and localities could have important implications for families and the effectiveness of services. The nature of the service delivery system could affect which families get services; how easily services are accessed; how many services, programs, and agencies a service coordinator has to coordinate; and how much these services cost. Some early intervention systems may be more family friendly than others. Some

organizational arrangements may enable families to receive services earlier or to access more or different services. Some systems may serve more children or different types of children.

To describe variations in the organization of early intervention, we developed a framework that identifies several key dimensions of state and local systems: what constitutes a local jurisdiction; the extent of within-state variation; interagency issues, including coordination and the agencies that are involved; eligibility criteria, including how at-risk populations are served; models of intake; and models of service coordination. The dimensions we describe here were selected because they are potentially significant for children and families and because we had systematic data on them across a large sample of states. This list of system dimensions does not include all dimensions that are potentially relevant to service delivery, such as transition models, for example.

The data reported here were collected as part of the National Early Intervention Longitudinal Study (NEILS). NEILS is a multiyear study of a nationally representative sample of more than 3,300 children and families newly enrolled in early intervention services. The sample for the study was recruited from nearly 200 programs in 93 counties in 20 states across the United States. The primary focus of the study is on children, families, and their services (Hebbeler and Wagner, 1998).

As part of recruitment for NEILS, it was necessary to collect detailed information about the intake and eligibility determination procedures and initial service coordination models in each participating county. Families were recruited into NEILS at or shortly after the completion of the initial Individualized Family Service Plan (IFSP) process. The recruitment activities provided a rich look at variations in the organization and operation of early intervention, including how the local systems conduct intake, determine eligibility, and develop the initial IFSP.

The purpose of this report is to provide descriptive information on variations in selected features of state and local early intervention systems. We also raise questions about how variations on these dimensions could be significant to children and families. Ultimately, we will use the NEILS data to explore the relationship between how state and local early intervention systems are organized and the experiences and outcomes for children and families.

# METHODS

## Sample

A sample of 20 states was selected for the study. The nine states serving the largest number of children in Part C were selected for the sample with certainty: California, Florida, Illinois, Massachusetts, New York, North Carolina, Ohio, Pennsylvania, and Texas. At the time of the state sample selection (1997), these nine states served about 60% of all Part C children in the country. To select the remaining states, the country was divided into three regions, and states were selected from each region. The additional 11 states selected were: Arkansas, Colorado, Hawaii, Idaho, Kansas, Maryland, Michigan, Minnesota, New Mexico, South Carolina, and South Dakota. The 20 NEILS states are diverse with regard to population, region of the country, lead agency, whether they serve at-risk children, and the percentage of the population from birth to age 3 served in Part C.

The concept of "locality" within the context of Part C implementation is difficult to describe because of the within-state variation in how Part C is being implemented, as described in the results section below. Although all states are divided into local jurisdictions for the provision of services, the nature and size of these jurisdictions vary from state to state and within states. For the NEILS sample, counties were selected as the local sampling unit because they exist in all the states, the boundaries of counties are clear and do not overlap, and many public service-providing agencies are organized by counties.

Three to 7 counties per state were selected to recruit families for the study, for a total of 93 counties in the 20 states. Counties were selected randomly, the probability of selection being proportional to the size of the birth-to-age-3 population in the county, with the additional criterion that at least 10 new children be projected to be served annually under Part C in a county. This latter provision was necessary for efficiency and cost-effectiveness in sample recruitment efforts.

If one or more of the selected counties in a state declined to participate in the study, an alternate county was selected as a replacement from counties preselected to have the probability of selection closest to the original counties. Additional information about the sampling procedures is presented in Hebbeler and Wagner (1998).

## Data Collection and Analysis

Information about the organization of early intervention in the sample states and localities was obtained through telephone conversations with state Part C coordinators and a variety of local program personnel who were involved with intake and service provision and who could describe the local organization and its procedures for intake, eligibility determination, and service coordination. State and local documents, such as lists of providing agencies and annual reports, also were reviewed.

In conducting the analysis, state and local information was reviewed and discussed extensively by the research team, and information on each dimension was tabulated for each of the states. Cross-site comparisons then were made to identify similarities and differences in the service delivery systems, and state case reports were developed. The case reports and the descriptions included in this report were reviewed by the Part C coordinators for verification.

# RESULTS

## Examples of State Early Intervention Systems

No two states studied are the same on all dimensions of their early intervention service delivery systems. We found similarities among states on some system dimensions, but the dimensions are assembled in so many different ways that the resulting systems look very different. Furthermore, as discussed later in this section, one of the salient dimensions on which states differ is the amount of within-state variation in local systems. Some states are relatively uniform from locality to locality; others show substantial local variation.

We begin with brief case reports on three state systems to provide the reader with an overall sense of the range of ways in which states are organized for early intervention. These reports are followed by a description of each organizational dimension studied and the ways in which states differ on that dimension.

### Texas

In Texas, the lead agency is the Interagency Council on Early Childhood Intervention. Along with eight parents, seven state agencies are represented on the agency's Board. The lead agency funds 65 local public and private agencies to provide early intervention services. The state is divided so that each contracted agency serves a geographic area, with no overlap in service region and no area without a service agency. In urban areas, there can be numerous agencies within a single county. Dallas, for instance, has been divided into seven areas, each served by a different agency. In less populated areas, a single agency provides services for the entire county. This system provides a single point of contact within the local area, although the geographic sizes of the areas vary considerably. Intake, service coordination, evaluation and assessment, and early intervention services are provided primarily by each local agency through its own employees. Local education agencies (LEAs) are early intervention providers in some localities.

Texas does not serve at-risk children through Part C. The lead agency, however, funds Follow-Along or tracking programs for children who are ineligible for comprehensive early intervention services or for families of eligible children who decline the more comprehensive services offered to them.

### South Dakota

The Department of Education is the lead agency in South Dakota. The state is divided into regions, which are further subdivided into 22 local interagency networks for the purpose of providing early intervention services (referred to as Birth-to-Three Connections). Each of these local networks receives Part C funding from the state Department of Education to administer the early intervention system in its area. Some of these networks encompass a single county, but most are multicounty jurisdictions that were created by the local areas for the purpose of early intervention. These geographic areas do not correspond to the jurisdictions of other public

agencies (e.g., education districts, health agencies). Each network has a single point of entry for initial referrals to the early intervention system. Many of the networks are in local education cooperatives, but they may also be under the jurisdiction of a private not-for-profit agency (e.g., Easter Seals) or a public agency (e.g., a mental health center).

The staff of these local interagency networks, employees of the network's local agency or program, take referrals, provide the initial service coordination, arrange for eligibility determination, and complete the initial IFSP. Many of these same staff serve as ongoing service coordinators for families (this is the primary service coordination model), but service coordination may be transferred to a private provider after the initial IFSP has been completed.

Early intervention services are provided by a mixture of public (mainly education agencies) and private agencies/providers (hospitals, medical centers, individual therapists in private practice). About 40% of services are provided through education agencies and about 60% through private agencies.

South Dakota does not serve at-risk children, nor does it have any other state program for such children.

### North Carolina

The lead agency in North Carolina is the Department of Health and Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MH/DD/SAS). Other public agencies also are involved in the early intervention system, particularly North Carolina Public Health, which is heavily involved in the initial intake, service coordination, and tracking of high-risk infants and toddlers. Public Health operates a network of 19 Developmental Evaluation Centers (DECs), where developmental evaluations of infants and toddlers are conducted. North Carolina serves children of "high risk potential," those who have three or more indicators of risk, through Part C.

Entry into the early intervention system is through a single point of entry in each local area, with the local MH/DD/SAS agency serving as the local lead agency (there are 40 across the state), but working in an interagency consortium with the Public Health staff. This consortium arranges for the initial service coordination and for the assessments to be conducted by the DEC, and makes the eligibility determinations. These intake points are predominantly multiple-county jurisdictions.

Both the initial and ongoing service coordination are provided by staff from the local area MH/DD/SAS agency (for about 80% of families) or by Division of Public Health staff (for the other 20% of families). The service delivery system in North Carolina is a mixture of public and private providers. For about 60% of services, staff from the MH/DD/SAS program are the providers; the remaining 40% of services are provided by private programs or providers under contract with the local MH/DD/SAS agency. Local education agencies are not involved in the early intervention system in North Carolina.

## Dimensions of Variation in State Early Intervention Systems

This discussion focuses on variations among state early intervention systems in local system characteristics, eligible populations served, and agencies involved in service provision.

### Local Systems

#### What Constitutes a Local Jurisdiction for Early Intervention?

All the sample states are subdivided into local jurisdictions for the provision of early intervention services. In some states, such as Ohio, New York, and Maryland, the local jurisdictions are counties. In some states with county-based systems, some of the counties have been combined into multiple-county local jurisdictions, whereas densely populated counties have been subdivided into several smaller jurisdictions. In some states, the local jurisdictions match the existing jurisdictions of the lead agency. For example, in South Carolina, there are 13 health districts under the Department of Health and Environmental Control, and these are the same 13 districts used for the administration of early intervention. In other states, new local jurisdictions have been created for the early intervention system. In South Dakota, for example, 22 local interagency networks were created to administer early intervention with Part C funding received from the lead agency.

In some states, the local areas have non-overlapping boundaries, as with county-based systems; one can represent all early intervention local areas on a single map of the state. In other states, the entities providing early intervention have different boundaries, and more than one map is required to clearly show the overlapping local jurisdictions. For example, in Michigan, both health and education agencies provide early intervention services, but these two agencies divide the state up differently. In California, the lead agency contracts for services with 21 regional centers. These regions do not correspond to the boundaries of local education agencies (LEAs), which also provide early intervention services. In Massachusetts, a network of programs provides early intervention services under contract with the state. The programs' boundaries overlap, and families have the choice of entering early intervention and receiving services from any program in the state.

#### Within-State Variation in Local Systems

Not only do early intervention systems vary from state to state, in some states they also vary significantly from one local jurisdiction to another. Some states have delegated the responsibility for designing the local system to the local area; not unexpectedly, this approach can result in local systems that vary significantly across the state. Other states have local variation because the localities have had different systems for many years, and these historical differences persist.

The states that have the least variation have the same agencies or the same mix of agencies performing the same roles across the state, similar intake procedures, and similar models for service coordination. For example, each local area in Illinois has an entity called "Child and Family Connections" that is responsible for intake and connecting the family with a public or

private service provider in the area. These entities are under contract with the state lead agency. South Carolina has an entity called "Babynet" that plays a similar role. In New York, all families enter early intervention through the office of the Early Intervention Official, which in almost all counties is located in the local health unit. Families then receive their early intervention services from private providers. North Carolina and Florida are further examples of states in which the early intervention systems have similar characteristics. Obviously, the early intervention systems in large cities in these states differ somewhat from systems in rural areas, but some of the key dimensions of the state's approach to service provision remain the same.

In Ohio, each county has a county collaborative group that is responsible for establishing an effective early intervention system. Accordingly, the systems in this state differ from county to county. In some areas, intake can occur through several points of entry, whereas in others, it is more centralized. Private agencies play a more substantial role in intake and service provision in some areas than in others. Similarly, in Maryland, the local governing authority has substantial responsibility for the structure of the local system, so that some localities have education as a local lead agency, some have health, and some have other public agencies configured to coordinate local service delivery to children and families. In California, through a long-standing state policy, LEAs are a key provider to a substantial number of children and families in some localities, yet serve only a small proportion in other places.

## The Eligible Population

### Definition of Developmental Delay

The federal law stipulates the general parameters for states to follow in defining the criteria for eligibility for Part C services but allows each state some discretion in determining the criteria and in defining developmental delay. The recently reauthorized federal law (20 U.S.C. §1432), as amended by the Individuals with Disabilities Education Act of 1997, states that "The term 'infant or toddler with a disability' (a) means an individual under 3 years of age who needs early intervention services because the individual—(i) is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or (ii) has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay."

A note to the current federal regulations (34 C.F.R. §303.16) elaborates on the phrase "a diagnosed physical or mental condition that has a high probability of resulting in developmental delay" with some illustrative examples. Examples of such conditions include: chromosomal abnormalities; genetic or congenital disorders; severe sensory impairments, including hearing and vision; inborn errors of metabolism; disorders reflecting disturbance of the development of the nervous system; congenital infections; disorders secondary to exposure to toxic substances, including fetal alcohol syndrome; and severe attachment disorders.

The federal law allows states to decide whether they will serve children considered to be at risk. The legislative language (20 U.S.C. §1432) states that "The term 'at-risk infant or toddler' means an individual under 3 years of age who would be at risk of experiencing a substantial

developmental delay if early intervention services were not provided to the individual." The current federal regulations contain a note (34 C.F.R. §303.16) further stating that "children who are at risk may be eligible under this part if a State elects to extend services to that population, even though they have not been identified as disabled." Again the regulations provide guidance with illustrative examples: "In defining the 'at risk' population, States may include well-known biological and environmental factors that can be identified and that place infants and toddlers 'at risk' for developmental delay. Commonly cited factors include low birth weight, respiratory distress as a newborn, lack of oxygen, brain hemorrhage, infection, nutritional deprivation, and a history of abuse or neglect. It should be noted that 'at risk' factors do not predict the presence of a barrier to development, but they may indicate children who are at higher risk of developmental delay than children without these problems."

The sample states vary in the definition of "developmental delay." Some states refer to "significant delay" with no specific criteria of the amount of delay needed for eligibility. Other states have precise criteria for the percentage of delay in terms of months delayed or standard deviations delayed on developmental assessment instruments that qualify for eligibility. Some states have different delay criteria for infants less than 12 months old versus older toddlers (e.g., Massachusetts, Texas). Furthermore, these specific delay criteria vary across states; for instance, some states specify a criterion of 1.5 standard deviations below the mean on a standard assessment instrument; others have set 2 standard deviations below the mean as the criterion. States that include percentage delay in their definition also have varying thresholds (e.g., 20%, 25%, 30%, 40%, 50% in one or more areas of development). Many states include both percentage and standard deviation criteria, in recognition of the variations in developmental assessment instruments. Finally, in some states, there are different definitions of delay in order to be eligible to receive services from different agencies. For example, to be eligible for early intervention services through the LEAs in Michigan, an infant or toddler must meet Part B criteria. Similarly, in California, LEAs and regional centers use different delay criteria for determining eligibility for the services provided by their agencies.

The sample states also vary in the specificity of definitions of "diagnosed physical or mental condition that has a high probability of resulting in developmental delay." Some states have a list of the established conditions included in their eligibility definition, but some conditions that might be considered as "at risk" conditions (e.g., low birth weight of a specific amount) are included in some states as diagnosed conditions. In many states, "informed clinical opinion" can be used to determine eligibility, and "atypical development" as determined by a single professional or by a multidisciplinary team's consensus judgment also is an eligibility criterion, whereas in other states, these criteria are not explicitly included.

### Serving At-Risk Children

States have discretion to include children who are "at risk" in their eligibility criteria for receipt of Part C services, although not many states do (Shackelford, 1998). The sample of NEILS states was intentionally selected to include some states that serve at-risk children through Part C (e.g., California, Hawaii, Massachusetts, New Mexico, North Carolina). Here again, the precise criteria for determining eligibility vary across states. Some states specify a list of

biomedical and/or environmental conditions, but the number and kinds of risk factors needed for an eligibility determination for Part C services vary from state to state.

Although only a few states include the at-risk population in their Part C eligibility definition, other states may have programs for at-risk children. Some states that do not serve at-risk children through Part C nevertheless have non-Part C systems to track high-risk infants and toddlers and monitor their developmental progress. Some states provide direct services to these children and families, as well. For instance, Florida has a state-funded tracking and monitoring program for at-risk children, many of whom are identified shortly after birth and are graduates of neonatal intensive-care units. The families receive a Family Service Plan and may receive many of the same kinds of assessments and services as other infants and toddlers served under the Part C system, although they are not formally in the Part C system. California, which serves at-risk children under Part C, also has a non-Part C program under the Department of Health that tracks and monitors the developmental status of high-risk infants. Similarly, Pennsylvania tracks and monitors high-risk infants and toddlers who have any of five risk factors. The program is under the same public agency that provides Part C services. Ohio has a statewide program, known as Ohio Early Start, that provides services for children birth to 3 who are at risk for abuse, neglect, or future developmental delay. At the state level, this program is housed with the same office that administers the Part C program.

## Agencies Involved in Providing Early Intervention Services

The goal of building an interagency system is a central feature of the vision of the Part C legislation (Gallagher, LaMontagne, and Johnson, 1994; Garland and Linder, 1994). Before P.L. 99-457, a variety of agencies in different states provided early intervention services to various segments of the population of infants and toddlers with disabilities. One study, completed before the legislation's passage, found that states had an average of three to four agencies with primary responsibility for managing birth-to-6 services (Meisels, Harbin, Modigliani, and Olson, 1988). One of the lessons learned in the early years of Part C implementation was that not all states had multiple, uncoordinated agencies providing early intervention services. Some states, in fact, did not need to "glue" the pieces of their system together. In these states, there were few agencies providing services, so that the state's task was to expand the services and the providers of service (Hebbeler, 1997). More than a decade after the law's passage, which agencies are providing early intervention services?

### The Role of Education Agencies

Historically, departments of education were major providers of early intervention in some states because their state special education laws addressed infants and toddlers. Seven states (Iowa, Maryland, Michigan, Nebraska, New Jersey, Oregon, and South Dakota) mandated the provision of special education services from birth at the time of P.L. 99-457's passage (Minnesota had a birth mandate under education shortly after passage, and Texas had a birth mandate for early intervention services, but not under education). In these states, infants and toddlers with disabilities were provided special education services and entitled to all the rights of school-age children in special education. In a number of states, the mandated age for special education was

3, but most states permitted special education to be made available to some infants and toddlers before the mandated age (Fraas, 1986).

The sample states vary in both the extent and manner of involvement by education agencies in the early intervention system. Education can be the state lead agency and also a major service provider, or it can play little or no role in early intervention. Many of the states in which education agencies are not involved or only minimally involved in the provision of early intervention services are states in which departments of health or human services serve as the lead agency (e.g., Arkansas, Hawaii, Idaho, Massachusetts, New Mexico, New York, North Carolina, Ohio, Pennsylvania, South Carolina). Interestingly, in Colorado, where the Department of Education is the lead agency, LEAs rarely are involved in providing services.

More extensive, but varied, involvement of education agencies is seen in states like California, Illinois, Maryland, Michigan, South Dakota, and Texas, where some early intervention programs are operated by an education agency, typically a school district. In these states, education may serve some types of children or serve children in some localities. Besides education, other public and private programs also provide services, often with involvement through the department of health or another public agency. For example, in South Dakota, many of the local networks that receive Part C funding from the lead agency are education cooperatives, but there also are private programs, such as Easter Seals, and other public agencies, such as mental health centers. In Minnesota, the initial intake and service coordination, as well as the ongoing service coordination and service provision, are administered largely through LEAs, with some early intervention services provided by other agencies. In some states with significant education involvement, education agencies provide services to a minority of the state's children in early intervention. In other states, education agencies serve a majority of the children and families.

### The Role of Health Agencies

The role of state health agencies in Part C systems also is quite variable across the NEILS states, ranging from little or no responsibility for intake, assessment, or service provision to being the lead agency and taking a central role in many aspects of the early intervention system. The same states named above as having moderate or mixed involvement of education agencies are variable with regard to health agency involvement. Maryland, for example, has both education and health agencies designated as the local lead agencies throughout the state. There are roughly an equal number of jurisdictions with departments of health and education as their local lead agency, which is especially interesting given that Maryland was a birth mandate state when P.L. 99-457 was passed. Michigan and Minnesota also have combinations of involvement from local education and local health and social services agencies. Kansas is interesting with regard to health agency involvement in that the Department of Health and Environment is the lead agency, and although local health departments are involved in the early intervention service delivery system, none of them serve as the lead agency for the local early intervention network.

States with significant involvement of health agencies include Florida, Hawaii, North Carolina, and South Carolina. In these states, the state health agency is the lead agency, and the initial referral and intake system is coordinated with its statewide system. For instance, South Carolina's Babynet is housed in local health district offices. In Florida, most of the early intervention points of entry are

located in medical centers or hospitals. In Florida, however, after the initial IFSP is finalized, families receive most services through private programs. In Hawaii, the Department of Health administers the public programs providing early intervention services and contracts with private programs and providers. In North Carolina, intake and a large percentage of direct services are provided by units within the state MH/DD/SAS.

States with more limited involvement of health agencies tend to be those with non-health lead agencies. These include, for example, California, Colorado, Illinois, Minnesota, South Dakota, and Texas. However, there are states in which the state health agency is the lead agency for early intervention but the majority of the intake and service delivery activities are performed by other agencies or programs under contract with the health agency (e.g., Massachusetts, New Mexico, New York).

### The Role of Private Programs

A variety of private agencies have been involved historically in providing early intervention services to young children. Some of these, such as Easter Seals, ARC, or United Cerebral Palsy programs and programs for the deaf-blind, are associated with national or statewide associations focused on particular disabilities or age groups. Local areas vary substantially in the availability of private programs and their role in the delivery of early intervention services. Some areas rely heavily on private programs to provide early intervention services, whereas other areas have few or no private programs involved in their early intervention systems.

One model that involves private programs has intake being performed by a public entity, after which the family is connected to one or more private programs to receive early intervention services. In another model, the public agency oversees the referral and intake process but does so by contracting with private programs and providers to conduct assessments and develop IFSPs. Some private programs have an extensive multidisciplinary staff (e.g., infant specialists, speech therapists, occupational therapists, psychologists), whereas others have a narrower focus, such as a group of physical therapists in private practice or a single practitioner. In some areas, these private programs and providers coexist with public programs that also provide early intervention services.

Examples of states making extensive use of private programs for service delivery include California, Illinois, Kansas, New Mexico, New York, and Pennsylvania. In both California and New York, private programs provide services after a separate intake process. In New York, intake is conducted by a public agency, whereas in California, intake for many children is carried out by one of the regional centers, private programs that operate under contract with the state's lead agency, the Department of Developmental Services. The regional centers in turn may contract with other private programs and providers for the delivery of direct services. In New Mexico, the Department of Health contracts with private programs, which are responsible for providing, subcontracting for, or arranging for early intervention services..

Examples of states where private programs are incorporated as providers into the service delivery system, but on an equal or lesser footing compared with public programs, include Hawaii, Idaho, Maryland, Ohio, and South Dakota. In these states, private providers play an important role in the delivery of early intervention services, but so do public providers.

Yet another model of private program involvement is seen in Massachusetts and Texas. In these states, the lead agency contracts with a local entity for the operation of an early intervention program. Massachusetts contracts with 41 private vendors to operate 65 early intervention programs. In Texas, some of these local entities are public programs, whereas others are private programs. As discussed in the following sections, the contracted programs provide all aspects of early intervention service delivery, from intake through transition to preschool when children turn 3 years old.

It is difficult to discern a pattern of factors in the sample states that clearly predicts where private programs are used most extensively. As might be expected, private programs appear to be a resource more readily available to larger states and urban areas; however, some smaller states and rural areas also rely heavily on private programs for provision of early intervention services.

### Interagency Configurations

All states have state-level Interagency Coordinating Councils (ICCs) because the federal law requires it. Many states also have local ICCs. One of the functions of both councils can be to work through challenging interagency issues at a policy level, so that individual service coordinators and families do not face interagency barriers to service access (Rosenkoetter et al., 1995). The interagency challenges among early intervention programs and agencies differ substantially across states because the early intervention service system configurations differ.

We identified three major types of local interagency configurations in the sample states. The first and simplest configuration has a single program that provides all or most early intervention services. This configuration appears to minimize interagency challenges because there are no other agencies involved. This approach characterizes Massachusetts, New Mexico, and Texas and sparsely populated areas of some other states.

A second configuration involves a single public agency that contracts for services with one or more private programs in the local community. This arrangement requires that programs work together; however, the nature of the relationship between the buyer and seller of services is fundamentally different from an interagency relationship between two public agencies. States with this kind of configuration include Florida, New York, North Carolina, and Pennsylvania.

A third configuration, and possibly the most challenging for interagency coordination, involves two or more public agencies as well as private agencies providing early intervention services in a community. Some states with this configuration identify one agency or program that serves as the lead agency at the local level and thus has responsibility for local interagency coordination. As discussed in the next section, states with more than one public agency serving a community sometimes can have more than one way for families to get into early intervention because each agency enrolls families. States with more than one public agency as well as private agencies involved in early intervention include California, Kansas, Maryland, Michigan, Minnesota, and South Carolina.

This discussion has focused exclusively on interagency configurations involving agencies or programs providing early intervention services. Another type of interagency arrangement is the relationship between early intervention agencies and agencies that serve the same families in other

capacities, for example, Social Services or agencies providing public assistance, job training, or mental health services. We have not discussed these types of interagency arrangements because we did not collect information on them. Nevertheless, the nature of the interagency relationships between early intervention agencies and other public agencies could ultimately prove very important for many families.

## Receipt of Services

The system variations that are most visible to families are those that they encounter. In the following sections, we describe two components of the early intervention process that involve how systems work with families: intake and service coordination.

### Intake

Intake refers to the process through which families enter the early intervention system. The exact scope of the intake process varies, but generally it includes collecting basic family information, conducting an initial evaluation and assessments, making eligibility determinations, and developing the initial IFSP. In some localities, intake and service provision are carried out by the same agency or program. Alternatively, intake services can be provided by one program and subsequent services by another. We also have found that localities differ with regard to whether a family can enter the early intervention system and go through the initial IFSP process through a single point of entry for a given locality or through multiple agencies or locations.

The intake model in which one agency conducts some or all of the intake process and then connects the family with a second program exists in a number of states. In New York, for example, a public agency oversees entry into early intervention. It provides the initial service coordinator, who collects family information, helps the family select a provider for the evaluation and assessment and providers for services, and participates in the development of the IFSP. When intake is complete, the family begins services from a private provider. In South Carolina, Babynet takes the referral and begins the IFSP process. Later, families are connected with one or more early intervention service providers from a different program. This latter model also exists in Pennsylvania and Florida.

In Hawaii, the initial referral can go to a centralized 1-800 number, and the agency taking this information refers the family to an early intervention program that undertakes the evaluation and assessment process and develops the IFSP. Similarly, in Massachusetts and Texas, referrals go directly to early intervention programs that carry out the intake functions and provide services.

Intake in local communities also differs with regard to how many different ways there are to enter the early intervention system. In a system with a single point of entry, all families living within a defined geographic area enter early intervention through the same agency. In a system with multiple points of entry, there is more than one way to enter the service system. The systems in Florida, Idaho, Illinois, Kansas, Maryland, New York, and South Carolina are single-point-of-entry systems, in which all families entering early intervention in a county or region begin the process at the same agency. In contrast, early intervention systems in California, New Mexico and Michigan have multiple points of entry. In California, children who are blind, deaf, or

severely orthopedically impaired enter early intervention and receive services only through an LEA. Children with other disabilities may enter through a different agency or through the LEA. In Michigan, children who have a disability that will make them eligible for special education at age 3 enter and receive early intervention through an LEA, whereas children who have other disabilities or are less delayed enter and receive services through the health department or another public agency. In New Mexico, referrals can either go directly to the private early intervention program or to the local county health department office.

### Service Coordination

The federal legislation requires that families be provided with service coordination, a topic that is receiving increasing attention in the early intervention field (e.g., Bruder and Bologna, 1993; Dinnebeil, Hale, and Rule, 1996; Dinnebeil and Rule, 1994; Roberts, Akers, and Behl, 1996; Romer and Umbreit, 1998). Service coordination is intended to produce a more cohesive set of services by ensuring that there are no gaps or duplications in the services families receive.

We identified several models of service coordination in the NEILS sample states. Some of these models were identified by Harbin et al. (1998) in their examination of early intervention service utilization, and by Hurth (1998) in her review of caseloads for service coordination in different states. Approaches to service coordination differ with regard to whether:

- The family receives a new service coordinator after the initial referral and intake process is completed ("preliminary-to-ongoing" versus "single service coordinator" model).
- The service coordinator is employed by an independent agency or by the agency providing most of the family's other early intervention services ("independent" versus "employee" model).
- The service coordinator also works with the family in any other capacity besides service coordination ("multiple functions" versus "designated").
- The service coordinator's caseload includes narrow versus wide ranges of age and disability status of the individuals served.

In some localities, a family is assigned a preliminary (interim or intake) service coordinator for intake, who later is replaced by another ongoing service coordinator who coordinates the actual delivery of services. We call this the "preliminary-to-ongoing" model of service coordination. In some counties in Ohio, a preliminary service coordinator from an intake agency assists the family with the process of enrolling in early intervention, including starting the IFSP. This preliminary service coordinator is replaced later by service coordinators associated with the providing agency. Service coordination is structured similarly in South Carolina. In New York, the preliminary service coordinator is assigned as part of the intake process, and the family has the option of having a new service coordinator when the family is connected to early intervention services.

In other localities, the same service coordinator continues with a family through intake and service provision. This "single service coordinator" model is found in South Carolina and Pennsylvania, where the public lead agency responsible for the initial intake assigns the service

coordinator (or contracts with an agency to do service coordination). The service coordinator remains in that role throughout the family's participation in early intervention, even after the family transfers to a private program for services (although in South Carolina, some families have the service coordination function transferred to another service provider). The situation is similar for most families in California, where service coordination may be carried out by a private agency under contract to the lead agency, but the other early intervention services are provided by other private programs. For a smaller percentage of families in California, the LEAs perform the service coordination role and also are responsible for providing other direct services. In New Mexico, the family gets to choose whether to remain with the individual who provided interim service coordination or choose a new ongoing service coordinator.

Another dimension of the service coordination model is whether the person providing service coordination is employed by an independent agency or by the program providing the other early intervention services to a family. Some states, (e.g., California and Pennsylvania) have contracts with private agencies that have service coordination as their sole or primary function. In other states (such as Massachusetts, New Mexico, and Texas), the service coordinator is an employee of the providing program. The employee model also applies to service coordination in a number of states in which education is the lead agency or is a major provider of services (e.g., Maryland, Michigan, Minnesota, South Dakota).

There could be advantages and disadvantages to having the service coordinator be an employee of the program providing direct services to children and families. When the service coordinator and all or most of the other early intervention service providers work for the same program, the task of coordination could be substantially simplified. Note that the coordination can still involve multiple disciplines when the program's staff is drawn from a variety of disciplines. However, the coordination does not require extensive linkages across agencies or knowledge of early intervention services from other programs. Furthermore, the service coordinator has regular contact with all or most of the other early intervention providers and thus potentially can coordinate more effectively. Harbin et al. (1998) concluded that the least effective models of service coordination involve a service coordinator from an agency other than the service-providing agency because in this type of approach the service coordinator sees families too infrequently and is too removed to develop an effective relationship with families.

A possible advantage of the independent model, voiced by some providers in areas that use the model, is that the service coordinator's independence may result in a more comprehensive set of services that address the needs of both the child and family. By being independent from the program providing the other services, service coordinators may be in a better position to consider and share with families a wider array of community-based program options, services, and resources than if they were employees of the program. Moreover, service coordinators may be less able to serve as the family's advocate in the employee model.

Another dimension of variation in service coordination is whether the service coordinator has that single function or whether s/he has other roles in providing early intervention services to a family. Hurth (1998) refers to the former model as a "dedicated" service coordinator. In this model, service coordinators may have specific training, skills, knowledge, and experience in helping families to identify the range of services and programs they might need, including non-Part C services. In this model, service coordinators have no other responsibilities than service

coordination (e.g., Pennsylvania, for many families in California, for some families in local Infants and Toddlers Programs in Maryland). Some states with this model have service coordination agencies under the state's public agencies of human services, mental health, developmental disabilities, etc., and these agencies may employ staff with backgrounds and experience in case management. Service coordinators in the "multiple function" model also serve in some other direct service role for the family, such as infant specialist or occupational therapist. They may have less training or experience in service coordination than coordinators in the dedicated model, but they also may have a stronger relationship with the family because of their multiple roles and extent of involvement. The multiple function model also reduces the number of service providers with whom the family must interact. Thus, for children and families needing services from a single early intervention program only, having a primary service provider serve as the service coordinator may be simpler. On the other hand, for children and families needing multiple services from multiple agencies, having an independent, dedicated service coordinator may be more effective, particularly if the service coordinator has more time and experience in obtaining services across agencies.

Finally, another dimension of variation in service coordination noted in the sample states is whether the service coordinator serves only infants and their families, children of all ages, or even the full range of the age spectrum. Employees of early intervention programs typically serve only young children and their families. Employees of service coordination agencies may serve a more diverse client population, especially in sparsely populated areas. Systems in which service coordinators handle broader age ranges might face additional challenges around personnel training and differing requirements and regulations for the duties of the service coordinators (e.g., timelines for developing service plans, requirements for mandated contacts with families, types of services to be coordinated, personnel requirements, caseloads, etc.).

## SUMMARY AND REMAINING QUESTIONS

The qualitative data presented in this report indicate that there is considerable variation along a number of dimensions of states' early intervention systems. We have seen that states differ with regard to how they are divided for the administration of early intervention, the extent of within-state variation in local systems, the eligibility criteria for who is served, the type and number of agencies involved in providing early intervention services, the ways agencies have coordinated their efforts, and models of intake and service coordination. The significance of many of these variations for children and families is not clear. Some systems appear to be more family friendly and might be easier for families to negotiate. Some systems may provide more choices for families or access to a broader array of services. Some systems could be more costly. Some arrangements may be better for making the transition into preschool special education. Some systems appear to be more consistent with the vision of the legislation. However, appearances may be deceiving. The ultimate test of the early intervention system is whether it produces positive outcomes for children and families, which is the primary intent of the legislation.

As the NEILS data about child and family outcomes, personnel and service characteristics, and program costs become available (data from family interviews, service records, and service provider and agency director surveys), we will examine the relationship between outcomes and the system variations we have described. Little is currently known about these kinds of interrelationships (Bailey, Aytch, Odom, Symons, and Wolery, 1999; Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker, and Wagner, 1998). The following are examples of the kinds of questions we will be addressing about system variations.

### Within-State Variation

- Do families in states with more within-state variation differ in their perceptions of the early intervention system?
- Are child and family outcomes more consistent in states with limited within-state variation?

### Defining the Eligible Population

- Do states with different eligibility criteria serve different types of children or serve similar children at different ages?
- Do states that serve at-risk children tend to enroll a greater proportion of children into early intervention at younger ages?
- Do states that serve at-risk children serve different types of children and disability categories (e.g., serve more speech-delayed children; greater proportions of low birth weight, premature infants; etc.)?

- Do children's long-term outcomes vary depending on whether or not the state serves the at-risk population?

### Agencies Involved in Providing Services

- Do families' ratings of early intervention services vary as a function of how many and which local agencies are involved in early intervention?
- Do areas with involvement of different agencies have different patterns of early intervention services?
- Are the types of services that families receive different for states with multiple versus single agency involvement in the early intervention system?
- Is the medical community more involved in referral and service provision when health agencies are significant providers of early intervention services?
- Are variations in costs of early intervention services related to private versus public agency involvement?
- Do families in states with extensive involvement of private agencies have different patterns of services than those in states with little or no involvement of private agencies?
- Do child and family outcomes vary depending on whether systems have extensive use of private versus public agencies?
- Do systems with a high degree of private-agency involvement tend to serve children in more natural environments?
- Do families in states with education as the lead agency have a smoother transition at age 3?
- How smooth is the transition at age 3 for families in states with exclusive reliance on private agencies for service provision?

### Receipt of Services

- Do families' experiences and satisfaction with the process of entering early intervention differ substantially across states and localities as a function of the variations in intake procedures and organization?
- Is family satisfaction with the intake process related to whether the system has single or multiple points of entry?
- Are children entering early intervention earlier in states and communities with single or multiple points of entry?
- Do the patterns of services differ for families in communities with single versus multiple points of entry?

- Do families report greater satisfaction with their service coordination in systems in which the service coordination is part of the program that delivers the direct services?
- Are the types of services provided to families different under different models of service coordination?

Almost nothing is known about the relationship between the nature of early intervention systems and the outcomes experienced by children and families. As we have described, the variation in how early intervention services are organized from state to state and locality to locality is considerable. It is reasonable to hypothesize that some of these arrangements are better suited to providing effective services than others. The first task in examining any possible relationships is developing a framework that identifies some of the potentially important dimensions of early intervention systems. The second task is to characterize states with regard to those dimensions. This paper presents both a framework and state characterizations. Subsequent analyses from NEILS will test their utility for understanding variation in child and family outcomes and ultimately improving the delivery of services.

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